

**MINUTES
of the
Governor's Council on Autism**

DATE: August 17, 2005

LOCATION: Madison, Wisconsin

MEMBERS PRESENT: Nissan Bar-Lev, Heather Boyd, Terri Enters, Vivian Hazell, Rose Helms, Joan Ketterman, Debra Mandarino, Milana Millan, Paula Petit, Paul Reuteman, Glen Sallows, Pam Stoika, Michael Williams

STAFF PRESENT: Beth Wroblewski, Sandy Blakeney

GUESTS: Helene Nelson, Sinikka Santala, Donna Wong, Marge Pifer, Elaine Gundlach

The meeting came to order at 10:00 AM.

Beth Wroblewski, Supervisor of the Children's Services Section of the Bureau of Long-Term Support welcomed everyone and introduced Helene Nelson, Secretary of the Department of Health and Family Services.

Helene offered a formal welcome to the members of this new Council on behalf of Governor Doyle as well as the Department of Health and Family Services (DHFS). She reiterated the Governor's commitment to families and his interest in hearing parents' voices on the issues that affect children and families. Helene expressed her gratitude to the members for being willing to contribute their time and expertise to this important work of advising DHFS on the provision of services for children with autism and autism spectrum disorders (ASD) provided through the new Children's Long-Term Support Medicaid Waivers.

Council members spent some time introducing themselves and identifying their primary interests in regards to the mission of the Council.

Beth introduced Sinikka Santala, Secretary of the Division of Disability and Elder Services, who was able to join the Council for the first half of the meeting. Sinikka welcomed the members of the Council and thanked them for their willingness to work on these difficult issues.

Donna Wong, Assistant to the Governor, was present for the full meeting. Donna provided background on the Governor's Task Force on Autism and reviewed the Recommendations of the Task Force, out of which this Council has grown. Donna discussed the Governor's expectations for this Council, which include advising the DHFS on the program, and helping to make sure there are consistent standards throughout the State. The Council was provided with a copy of the

letter from Governor Doyle to Secretary Nelson announcing his development of this Council and outlining the issues and recommendations identified by the Task Force that he wants the Council to work on.

There was a question as to what action has been taken to date on the Task Force recommendation that the Department create an ombudsperson position. Beth reported that this responsibility was given to the Office of Strategic Finance (OSF) and they are finalizing a contract with the Marquette University Mediation Center. This will be added on to a contract that OSF already has with the Mediation Center for providing services for the Birth to 3 Program. This has been a highly successful program and is expected to work very well for the Children's Waivers. Final contract details are being worked out now.

The Council discussed the purpose and structure of the Council on Autism. The Council was provided with a handout that summarized the Mission of the Council (from the Governor's letter to Secretary Nelson). Members reviewed and discussed this document. There was discussion about the increase in numbers of children with autism or ASD over the past 12 years and the critical need to identify services for them throughout their lives. The Council also discussed the current makeup of the Council.

On the topic of how the Council should work - the decision-making process, the structure of the Council (e.g., whether or not there will be a Chair, Vice Chair, sub-groups, etc.), Beth presented examples of three groups with which she has worked, which have three different kinds of structure. Each has a "loose" parliamentary structure, following Robert's Rules of order to some degree, with provisions for dealing with a situation where a Council decision is needed on short notice. Members had many different and creative ideas about how this Council should be structured, and what some of the most important considerations should be, including:

- ❖ Agenda creation
- ❖ Meeting management (e.g., facilitation)
- ❖ Frequency of meetings
- ❖ Process for inviting guests
- ❖ Public comment

Sinnika Santala did point out that the Department has a number of individuals who are trained specifically in meeting facilitation and offered that one of those individuals could be assigned as the facilitator for this Council. The Council was in favor of this and a facilitator will be named for future meetings. ***(Note: since the meeting, Kris Freundlich has been assigned as the Facilitator for this Council, and she will begin this responsibility with the November, 2005 meeting.)***

Although there was a general feeling among members that they would not want to have sub-groups working on various issues, in this particular case a "motion" was put forward to have a small group research and discuss the various kinds of structure that might work and bring proposals back to the Council at their next meeting. Volunteers for this "By-Laws SubGroup" were Nissan Bar-Lev, Heather Boyd, Deb Mandarino, and Milana Millan.

Motion: (From Rose Helms): Forward the topic of meeting management to a subgroup to research and make proposals.

Second: Heather Boyd

Vote: All were in favor

A discussion followed during which members brought up issues that they were especially interested in having the Council consider and possibly make recommendations on for the Department. At the end of the meeting, a list was generated of all the topics that had arisen throughout the day and priorities were identified. Members also specified that they would like to have DHFS input as to which are top priorities for the Department. The first three items on the list below were identified as members' top priorities.

- **Exceptions Policies**
- **Children's Functional Screen/Level of Care**
- **Independent Evaluation & Assessment (enough diagnosticians, quality training for teams)**
- Travel Guidelines
- Services across Lifespan
- Standard County Services
- Education - DPI Partnership
- Staffing Issues
- Alternative Forms of Treatment & Service Delivery Models (rural issues)
- 3-Year End of Intensive In-Home Autism Treatment
- Access to Information for parents; e.g., guidance on how the waiver process works.

Marge Pifer and Elaine Gundlach from the Division of Health Care Financing joined the meeting after lunch. Elaine presented a draft of guidelines regarding independent evaluation of ASD diagnosis. The paper was titled **General Approach for Establishing a Specific Diagnosis of Autism Spectrum Disorder**. Discussion followed regarding the purpose behind this document and how it might be useful to providers and families. Elaine emphasized that the Council could be very helpful in the process of figuring out how to meet Legislative Fiscal Bureau requirements regarding diagnosis without delaying children's access to services. She requested that the Council review the document and she would welcome the chance to return to another meeting and hear their input.

The Council wrapped up with a look at possible next meeting dates and landed on three possible dates: September 16, September 23, and September 26. A final date will be confirmed and members will be notified.

Minutes Respectfully Submitted by
Sandy Blakeney
September 26, 2005